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The Cruel Mystery

**LUPUS**<sup>®</sup>  
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# LUPUS COMMUNITY RESOURCE GUIDE

Comprehensive Support  
and Services for People  
with Lupus

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## INTRODUCTION

Lupus is a chronic (long-term) autoimmune disease. An autoimmune disease is when the body attacks itself instead of just fighting germs. When this happens, it causes *inflammation*. When you have lupus, inflammation can happen in any part of your body.

In your joints or skin, inflammation can feel like swelling, redness, or pain. When inflammation affects an organ inside your body, it can feel different. For example, when inflammation attacks the brain, it can cause confusion. When it attacks the lungs, it can make it hard to breathe. Sometimes, inflammation from lupus can cause permanent damage to the body, so it's important to treat it as soon as possible.

### About the Lupus Foundation of America

The Lupus Foundation of America (LFA) is dedicated to improving the quality of life for all people affected by lupus through programs of research, education, support, and advocacy.

Since 1977, the LFA has made pioneering contributions toward ending the brutal impact of this misunderstood and unpredictable disease.

We have redefined lupus research beyond just awarding grants and are tackling lupus from every direction to identify the causes of lupus, discover better ways to control symptoms, and, ultimately, find a cure for lupus. We do this while providing care and support for everyone affected by this devastating disease and leading advocacy efforts to bring more funding for research and services.

### How To Use This Guide

This guide is designed to connect people with lupus and healthcare providers to vital resources and services to improve lupus disease management and health outcomes.

**Instructions: This guide is organized into sections to help you find the resources you need. Use the table of contents to navigate to different sections, and look for icons that indicate specific types of resources.**

When you're struggling, finding the resources you need can be overwhelming. Here are some helpful tips:

- Reach out to several assistance organizations. If you don't qualify for one program, you may qualify for a different one.
- Frequently check program availability. Fund availability often changes throughout the year.
- If you have other conditions or diseases, search for any funds available for those conditions.
- Look for other types of financial assistance programs (food, utilities, etc.) and free up your funds for medical care.

**NOTE: The Lupus Foundation of America does not endorse any community resource or guarantee the quality of services provided. This guide is intended to help you locate resources in your area. This resource guide is not exhaustive, and the resources are not listed in any specific order.**



## LUPUS COMMUNITY RESOURCE GUIDE

Many resources only have websites or require you to visit their websites in order to find a local program or a program near you. Here are some tips if you do not have a computer or internet access:

- Visit your local library, community center, or schools. Many of these places offer free access to computers with internet connection.
- If you have a smartphone, you can use your mobile data or find places with free Wi-Fi like the library, cafes, or other public spaces to access websites.
- Some nonprofit organizations or community programs provide access to computers and the internet.
- Ask a friend or family member to help you look up information or share their computer.

Use this guide to find financial assistance resources available. If you still need help, reach out to Lupus Foundation of America Health Education Specialists at 800-558-0121 or [Lupus.org/ask-an-educator](https://lupus.org/ask-an-educator).

### Key

Under certain resources you will find symbols that indicate other services resources that are available. Below is a description of what each icon stands for.



**Child Care Assistance**



**Dental**



**Disability Assistance**



**Employment Assistance**



**Food Assistance**



**General Financial Assistance**



**Health Insurance Navigation Assistance**



**Holiday Assistance for Toys**



**Housing & Utility Assistance**



**Medical Care Assistance**



**Mental Health Assistance**



**Transportation Assistance**



## Key Health Considerations for People with Lupus

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Living a healthy life is important for everyone, but it becomes even more important for those with a lupus diagnosis. Because lupus can be unpredictable with periods of flares (when lupus symptoms get worse) and remissions (when people with lupus feel better), it's important for people living with lupus to prioritize self-care and closely manage their health.

The good news is that taking a proactive approach to your health can help manage your symptoms and reduce the risk of complications. Some easy ways to be more proactive in your health include following your treatment plan, getting regular check-ups, and maintaining healthy habits - being conscious of the food you eat, getting physical activity, prioritizing your sleep, and managing your stress.

### **Schedule Regular Doctor Visits and Get Routine Lab Work**

It's no secret that lupus can be unpredictable, which is why it is important to see your rheumatologist for regular visits and get lab work. Regular visits with your doctor allows your care provider to monitor your lupus and identify any changes that may indicate the start of a flare. Your doctor can adjust your medications or treatment plan, if needed, to better manage your symptoms and minimize damage to your body. Your lab work is just as important as an office visit; it may detect changes before you feel any symptoms of a flare and can help your doctor to better manage your lupus.

Lupus can affect any organ in the body, including the kidneys. When lupus attacks the kidneys, it is called Lupus Nephritis (LN). LN is one of the most serious complications of lupus. Up to 60% of lupus patients will develop LN, and it usually develops within five years from when lupus symptoms first appear. In its early stages, symptoms can go unnoticed, and if it is not treated, the symptoms can get worse and lead to kidney failure. Therefore, it is important that you see your lupus doctor regularly and receive routine LN screenings at every visit. It can be as simple as a urine test! Learn more about lupus nephritis [Lupus.org/L-N](https://lupus.org/L-N)

By staying on top of your health with frequent doctor appointments, you can better manage your lupus, minimize flare-ups and maintain your overall well-being. Learn how to get ready for your next doctor's appointment [Lupus.org/dr-appts](https://lupus.org/dr-appts)

### Follow Your Treatment Plan and Take Medications as Prescribed

Lupus treatment is different for everyone. That's because no two cases of lupus are the same — each person experiences lupus differently. That's why it's so important to work closely with your lupus doctor to come up with a treatment plan that's right for you. Treatments for lupus generally focus on:

- Managing your symptoms, like joint pain or fatigue
- Reducing inflammation in the body
- Keeping your immune system from attacking healthy cells (called immunosuppression)
- Preventing or treating lupus flares
- Limiting damage to your organs
- Increase your lifespan
- Taking care of your mental health and well-being

Be sure to talk with your doctor about your medications and any concerns you may have. Staying on top of your medications is a good way of managing lupus, but keep in mind that your treatment plan can change depending on how you respond to it.

Treating lupus is complex, and it's normal to need to make changes to your treatment plan from time to time. Your plan might also change if your personal goals for treatment shift.

Remember, you know your body best — and you have a say in your care. If something isn't working for you, speak up. It's okay to change your mind about a medication or therapy, but always talk with your doctor first. Making changes on your own — like stopping a medicine or starting something new — can be risky. Your doctor can help you adjust your care plan safely and effectively.

[Lupus.org/treating-guide](https://lupus.org/treating-guide)

### Protect Yourself from Infections

When you have lupus, you are at increased risk for all kinds of infections. Lupus itself can make infections occur more often and people with lupus sometimes take immunosuppressive medicines which can limit the body's ability to fight infections. Staying up-to-date on vaccines is one of the easiest steps you can take to protect your health — and it's especially important for people with lupus. Most people with lupus need the same vaccines as everyone else. Find out which vaccines are recommended for your age group. Then, ask your doctor about which vaccines you need. It's especially important for people with lupus to get the flu (influenza) and pneumonia shots.

### KEY HEALTH CONSIDERATIONS FOR PEOPLE WITH LUPUS (continued)

You should talk to your doctor about which vaccines are right for you. Interested in learning more about lupus and vaccines? Visit [Lupus.org/lupus-vaccines](https://lupus.org/lupus-vaccines)

Here are some other tips to help you stay healthy and avoid getting sick:

- Wash your hands often, especially before eating
- Avoid shaking hands
- Carry a small bottle of hand sanitizer and use it as needed
- Disinfect shared items at home or the office
- Avoid close interactions with people who have a cold, flu, or other contagious illness
- Get the rest you need
- If you do catch something contagious, stay home

More about protecting yourself from infections [Lupus.org/infection-prevention](https://lupus.org/infection-prevention)

### Stay Up to Date on Your Preventive Care and Screenings

Preventive health care helps find or stop serious health problems before they become bigger issues. Preventive care includes annual check-ups, vaccinations, cancer prevention screenings, and other tests such as a bone density screening. It is important to stay up to date on these screening tests when you have lupus.

An annual check-up, sometimes called your annual physical, allows your doctor to perform important general health screenings for high blood pressure, glucose, cholesterol, and other health conditions.

In addition to getting your vaccinations like your flu shot, you may need adult immunizations or boosters for things like Tdap (tetanus, diphtheria, and pertussis). As always, you should talk to your doctor before getting any vaccines.

Cancer screenings such as mammograms or colonoscopies are also important because most people don't experience cancer symptoms in the early, most treatable stages. Research has found that lupus is linked with an increased risk of certain cancers. Different screenings are recommended at certain times and intervals throughout your life, so it's important to talk to your doctor to see what screenings are recommended for you. Other preventive screenings include a Pap test (or Pap smear), or prostate specific antigen (PSA) tests.

Talk to your doctor about a bone density test (bone mineral density test) and if it is appropriate for you. You'll sometimes hear this test called a DEXA (dual-energy X-ray absorptiometry) scan. Studies have also shown that people with lupus have an increase in bone loss and fractures, which may be related to different medications used to treat lupus or result from lupus itself. Here's more about how you can manage bone loss [Lupus.org/protecting-bones](https://lupus.org/protecting-bones)

Preventive care and routine screenings help to monitor your health, detect any potential complications early, and minimize any risks associated with lupus and its treatment.



### Practice Healthy Habits

Living a healthy life is also important for those with lupus. Be kind to yourself and mindful of your body's limitations. Some easy steps are to simply be more conscious of the food you eat, be active, manage your stress, prioritize your sleep, and wear sunscreen.

Healthy eating can make a big difference in your lupus symptoms and your overall health. It can also help prevent or manage other health conditions you may have, like high blood pressure or diabetes. There's no special "lupus diet" you need to follow — just work on building a balanced diet with healthy foods you enjoy.

[Lupus.org/lupus-nutrition](https://lupus.org/lupus-nutrition)

It can be hard to get active when you have lupus symptoms — but physical activity can actually ease your symptoms and help you feel better! Regular physical activity can lower your risk of serious health problems like heart disease and osteoporosis (bone loss). It can also help reduce inflammation, reduce fatigue (feeling tired), boost energy, make muscles and joints less stiff, and help manage weight gain caused by lupus medicines, like steroids. [Lupus.org/staying-active](https://lupus.org/staying-active)

Sleep can make a big difference in how you feel — and healthy sleep habits are especially important for people with lupus. Getting enough sleep can help you prevent lupus flares, manage fatigue, and keep your body's immune system healthy. [Lupus.org/better-sleep](https://lupus.org/better-sleep)

Most people with lupus have what's called photosensitivity, which means they are sensitive to ultraviolet (UV) rays from sunlight and some types of indoor lighting. UV exposure can cause new skin rashes or sores (lesions), make existing skin problems worse, or cause other symptoms not related to the skin including joint pain, fatigue (feeling tired), and fever. It is important to take steps to protect yourself from UV exposure including limiting your time outdoors, applying sunscreen everyday, and wearing other protective clothing. Tips for managing sensitivity to light [Lupus.org/light-sensitivity](https://lupus.org/light-sensitivity)

Your emotional well-being is equally important. Learning to manage your stress may help prevent lupus flare-ups. Practicing relaxation techniques, such as mediation or focused breathing, can help you regain a sense of control, especially when lupus brings you discomfort. [Lupus.org/managing-stress](https://lupus.org/managing-stress)

And, don't forget to limit alcohol and quit smoking, if you partake in either.

Alcohol and Lupus [Lupus.org/drinking-alcohol](https://lupus.org/drinking-alcohol)

Quitting Smoking [Lupus.org/quit-smoking](https://lupus.org/quit-smoking)

### KEY HEALTH CONSIDERATIONS FOR PEOPLE WITH LUPUS (continued)

#### Manage Your Mental Wellbeing

Lupus affects more than just your physical health — it can impact your mental health, too. Keep in mind that you're not alone when it comes to dealing with lupus. Your lupus doctor, loved ones, support groups, and mental health professionals can all offer you support and help you find ways to take care of your mental wellness. Learn more about how to manage your mental health with lupus. [Lupus.org/mental-wellness](https://lupus.org/mental-wellness)

There are millions of people living with lupus who have found strength not just from friends and family, but from support groups (both in-person and virtual), events, and communities.

Look for people in your life who are willing to help out and be there for you. And keep in mind that they may not always be the people you would think! Many people will be able to help out in ways big and small, but finding those people who will always be there for you may be challenging, but is so important. **To find support near you visit** [Lupus.org/find-support](https://lupus.org/find-support)

#### DOCTORS WHO TREAT LUPUS

Many people who have, or suspect they have, lupus see a rheumatologist (or pediatric rheumatologist if they are a child or teen). This type of doctor specializes in diagnosing and treating diseases of the joints and muscles.

Since lupus can cause damage to many different parts of the body, you may see other types of doctors too, such as a:

- Dermatologist - a doctor who specializes in diseases of the skin, such as cutaneous lupus
- Cardiologist - a doctor who specializes in diseases of the heart
- Nephrologist - a doctor who specializes in diseases of the kidney
- Neurologist - a doctor who specializes in diseases of the brain and nervous system
- Gastroenterologist - a doctor who specializes in diseases of the gastrointestinal tract
- Pulmonologist - a doctor who specializes in diseases of the lungs
- Maternal-Fetal Medicine (MFM) Specialist - a specialized obstetrician/gynecologist who focuses on complicated and high-risk pregnancies

If you need help finding any of these health care professionals, see the Medical Providers section for more information.

## Additional Resources from the Lupus Foundation of America

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### Educational Materials

**Lupus Foundation of America**

**Website:** [Lupus.org](https://lupus.org)

Downloadable Lupus Information Packet:

[Lupus.org/packet-download](https://lupus.org/packet-download)

**Phone Number:** 800-558-0121

### Learn Ways to Better Manage Your Lupus

Lupus self-management skills can make your life with lupus a little easier.

**Website:** [Lupus.org/resources/learn-ways-to-better-manage-your-lupus](https://lupus.org/resources/learn-ways-to-better-manage-your-lupus)

### Local Support and Programs

The Lupus Foundation of America's network of chapters and regional offices across the country can help you find local events, resources, support groups and ways to get involved in the fight to end lupus.

**Website:** [Lupus.org/Chapters](https://lupus.org/Chapters)

### Lupus Nephritis Information Center

Our LN Information Center offers resources on understanding, diagnosing and treating lupus nephritis.

**Website:** [Lupus.org/resources/lupus-nephritis-resources](https://lupus.org/resources/lupus-nephritis-resources)

### Support Groups

Lupus Foundation of America support groups provide a safe and understanding environment where people with lupus can come together to ask questions, listen to others, or lend a helping hand.

**Lupus Foundation of America**

**Website:** [Lupus.org/find-support](https://lupus.org/find-support)

**Phone Number:** 800-558-0121

### Webinars and Other Events

Lupus Foundation of America hosts a variety of events, both in-person and virtual.

**Website:** [Lupus.org/find-events](https://lupus.org/find-events)

**Phone Number:** 1-800-558-0121

### Contact and Additional Support

**LFA Health Education Specialists**

LFA health educators can provide non-medical support, disease education, information and helpful resources to all people affected by lupus.

**Form:** [Lupus.org/ask-an-educator](https://lupus.org/ask-an-educator)

**Email:** [info@lupus.org](mailto:info@lupus.org)

**Phone Number:** 800-558-0121

## Spanish Language Resources:

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**Centro Nacional de Recursos sobre el Lupus** - Una colección de recursos e información sobre el lupus, para tomar decisiones informadas: [Lupus.org/resources-es](https://lupus.org/resources-es)

**Pregúntele a una educadora de la salud** - Nuestras especialistas en educación de la salud están disponibles para responder preguntas desde el diagnóstico hasta el tratamiento y el control. Llámenos al 800-558-0121 o llene el formulario en este enlace: [Lupus.org/educator-es](https://lupus.org/educator-es)

**Tome Control (Take Charge)** - una serie de correos electrónicos de 12 semanas diseñada para ayudar a las personas con lupus a controlar su enfermedad: [Lupus.org/tome-control](https://lupus.org/tome-control)

**Grupos de Apoyo Para Personas Hispanas** - Grupo de apoyo para personas Hispanas-Latinas que viven con lupus: [Lupus.org/find-support](https://lupus.org/find-support)

## MEETING YOUR BASIC NEEDS



### Food Assistance

#### AmpleHarvest

A nationwide non-profit that uses technology to educate and enable Americans who grow food in home and community gardens to easily donate their surplus harvest to registered local food pantries spread across all 50 states. To find a pantry, visit their website.

**Website:** [Ampleharvest.org/find-food/](https://ampleharvest.org/find-food/)

#### Child and Adult Care Food Program (CACFP)

CACFP is a federal program that provides reimbursements for nutritious meals and snacks to eligible children and adults who are enrolled for care at participating child care centers, day care homes, and adult day care centers.

**Website:** [FNS.usda.gov/cacfp](https://fns.usda.gov/cacfp)

#### Commodity Supplemental Food Program (CSFP)

CSFP works to improve the health of low-income persons at least 60 years of age by supplementing their diets with nutritious USDA foods.

**Website:** [FNS.usda.gov/csfp/commodity-supplemental-food-program](https://fns.usda.gov/csfp/commodity-supplemental-food-program)

#### Emergency Food Assistance Program (TEFAP)

TEFAP is a federal program that helps supplement the diets of low-income people by providing them with emergency food assistance at no cost.

**Website:** [FNS.usda.gov/tefap/emergency-food-assistance-program](https://fns.usda.gov/tefap/emergency-food-assistance-program)

#### Feeding America - Find Your Local Food Bank

Feeding America is the largest charity working to end hunger in the United States. They partner with food banks, food pantries, and local food programs to bring food to people facing hunger.

**Website:** [Feedingamerica.org/find-your-local-foodbank](https://feedingamerica.org/find-your-local-foodbank)

**Phone Number:** 800-771-2303

#### Findhelp

Find free or reduced-cost resources like food, housing, financial assistance, health care, and more.

**Website:** [Findhelp.org/](https://findhelp.org/)

**Other Resources Available:**



#### Food Distribution Program on Indian Reservations (FDPIR)

FDPIR provides USDA Foods to income-eligible households living on Indian reservations and to Native American households residing in designated areas near reservations or in Oklahoma.

**Website:** [FNS.usda.gov/fdpir/food-distribution-program-indian-reservations](https://fns.usda.gov/fdpir/food-distribution-program-indian-reservations)

#### Free and Reduced School Meals (FARM)

Parents and guardians of school-aged children can fill out an application to get free or reduced-priced meals at school for children enrolled in participating Head Start programs, Pre-K and K-12 school districts.

**Website:** [FNS.usda.gov/cn/applying-free-and-reduced-price-school-meals#](https://fns.usda.gov/cn/applying-free-and-reduced-price-school-meals#)

#### Meals on Wheels America

Meals on Wheels primarily provides nutritious meals, a quick safety check and much-needed human connection to homebound seniors. In some communities, additional services that keep seniors healthy and safe are also offered, like pet food delivery, senior center meal programs, home repair services and transportation. Each local program works with its own community's needs and resources to provide a community-specific solution.

**Website:** [Mealsonwheelsamerica.org](https://mealsonwheelsamerica.org)

**Phone Number:** 888-998-6325

#### Seniors Farmers Market Nutrition Program (SFMNP)

SFMNP is designed to provide low-income seniors with access to locally grown fruits, vegetables, honey, and herbs.

**Website:** [FNS.usda.gov/sfmnp/senior-farmers-market-nutrition-program](https://fns.usda.gov/sfmnp/senior-farmers-market-nutrition-program)



### Special Supplemental Nutrition Program for Women, Infants and Children (WIC)

WIC provides free healthy foods, breastfeeding support, nutrition education and referrals to other services, expanding options for your family.

**Website:** [FNS.usda.gov/wic](https://www.fns.usda.gov/wic)

**Phone Number:** Varies by State

### Supplemental Nutrition Assistance Program (SNAP)

SNAP provides food benefits to low-income families to supplement their grocery budget so they can afford nutritious foods essential to health and well-being.

**Website:** [FNS.usda.gov/snap](https://www.fns.usda.gov/snap)

**Phone Number:** 800-221-5689

**Other Resources Available:**



### Temporary Assistance for Needy Families (TANF)

TANF is a federally funded, state-run program. Also known as welfare, TANF helps families financially after experiencing hardship. Recipients may qualify for help with food, housing, home energy, child care, and job training.

**Website:** [USA.gov/welfare-benefits or ACF.hhs.gov/ofa/map/about/help-families](https://www.usa.gov/welfare-benefits-or-ACF.hhs.gov/ofa/map/about/help-families)

**Phone Number:** Varies by State

**Other Resources Available:**



### United Way 211

A free, confidential service available 24 hours, 7 days a week that provides local referrals for a wide range of needs, including housing, food assistance, health care, financial support, and more.

**Website:** [211.org](https://www.211.org)

**Phone Number:** 211

**Other Resources Available:**



## Housing and Utility Assistance

### Catholic Charities

Catholic Charities works to prevent homelessness by providing financial assistance and long-term support and strives to resolve issues that may lead to homelessness. Catholic Charities also provides help in the following areas: immigrant and refugee services, integrated health and nutrition, advocacy and social policy initiatives, disaster services, and foundational services.

**Website:** [Catholiccharitiesusa.org/](https://www.catholiccharitiesusa.org/)

**Phone Number:** 703-549-1390

**Other Resources Available:**



### Community Action Partnership (CAP)

The CAP's mission is to ensure all causes and conditions of poverty are effectively addressed and to strengthen, promote, represent, and serve the Community Action Network. They have various programs including energy partnerships.

**Website:** [Communityactionpartnership.com/](https://www.communityactionpartnership.com/)

### Find Shelter Tool

The U.S. Department of Housing and Urban Development's (HUD) Find Shelter tool provides information about housing, shelter, health care, and clothing resources in communities across the country.

**Website:** [HUD.gov/findshelter](https://www.hud.gov/findshelter)

### Healthcare Hospitality Network (HHN)

HHN provides free or significantly reduced cost lodging to patients and their families while receiving medical care away from their home communities with Healthcare Hospitality Houses.

**Website:** [HHNetwork.org/about-us](https://www.hhnnetwork.org/about-us)

**Phone Number:** 800-542-9730

### Low Income Home Energy Assistance Program (LIHEAP)

LIHEAP.org provides users with information and other resources that assist families with funds to help with energy costs.

**Website:** [Liheap.org/liheap-recipients](https://www.liheap.org/liheap-recipients)

## MEETING YOUR BASIC NEEDS (continued)

### National Energy Assistance Referral (NEAR)

The NEAR hotline is available if you need additional help finding your local energy assistance office. This is a free service.

**Website:** [Liheapch.acf.hhs.gov/referral.htm](https://liheapch.acf.hhs.gov/referral.htm)

**Phone Number:** 866-674-6327

### Salvation Army

The Salvation Army exists to meet human needs wherever, whenever and however they can help. They provide a variety of programs based on the needs of the community, you can use their website to search for programs in your area.

**Website:** [Salvationarmyusa.org/usn/](https://salvationarmyusa.org/usn/)

**Phone Number:** 800-SAL-ARMY (800-725-2769)

**Other Resources Available:**



### U.S. Department of Housing and Urban Development (HUD)

HUD provides information about renting (including assistance programs), local public housing, homeownership, and more.

**Website:** [Hud.gov/topics/rental\\_assistance](https://hud.gov/topics/rental_assistance)

### United Way 211

A free, confidential service available 24 hours, 7 days a week that provides local referrals for a wide range of needs, including housing, food assistance, health care, financial support, and more.

**Website:** [211.org](https://211.org)

**Phone Number:** 211

**Other Resources Available:**



## Safety

### Child Help Hotline

Available to help with next steps whether you are experiencing abuse, have witnessed abuse, or have questions about how to cope and heal from abuse.

**Website:** [Childhelpline.org](https://childhelpline.org)

**Phone Number:** 800-422-4453

**Text:** HELP to 800-422-4453

### National Domestic Violence Hotline

The National Domestic Violence Hotline provides essential tools and support to help survivors of domestic violence so they can live their lives free of abuse.

**Website:** [Thehotline.org](https://thehotline.org)

**Phone Number:** 800-799-7233

**Text:** START to 88788

### National Human Trafficking Hotline

The National Human Trafficking Hotline connects victims and survivors of sex and labor trafficking with services and supports to get help and stay safe.

**Website:** [Humantraffickinghotline.org](https://humantraffickinghotline.org)

**Phone Number:** 888-373-7888

**Text:** INFO to 233733

### Poison Control

If you took too much of a medicine, swallowed something that might be poisonous, splashed a product on your eye or skin, or inhaled fumes, Poison Control can help you get accurate answers online or by phone. Both are free and confidential.

**Website:** [Poison.org](https://poison.org)

**Phone Number:** 800-222-1222



## Transportation

### American Cancer Society Road To Recovery®

The American Cancer Society Road To Recovery® program gives free rides to cancer-related medical appointments. Trained volunteer drivers pick you up, take you to your appointment, and drop you off at home. All for free and all to make your days a little easier.

**Website:** [Cancer.org](https://cancer.org)

**Phone Number:** 800-227-2345

### Medicaid Transportation

Medicaid transportation is a critical service that assists beneficiaries with accessing covered Medicaid services and has a direct impact on health outcomes, coverage varies by state.

Website: [Medicaid.gov](https://www.medicaid.gov)

Phone Number: Varies by state.

### Mercy Medical Angels (MMA)

MMA provides information about all forms of charitable, long distance medical transportation and provides referrals to all appropriate sources of help to patients who cannot afford travel for medical care.

Website: [Mercymedical.org/](https://www.mercymedical.org/)

### Patient Access Network Foundation (PAN Foundation)

The transportation program assists patients with funds to access affordable and reliable transportation for their health needs. Services covered include airfare, car rentals, lodging, public transit, and more.

Website: [Panfoundation.org/funds/transportation/](https://panfoundation.org/funds/transportation/)

Phone Number: 866-316-7263

### Rides in Sight

Find local transportation programs by searching the Rides in Sight database.

Website: [Ridesinsight.org](https://ridesinsight.org)

Phone Number: 855-607-4337

### United Way 211

A free, confidential service available 24 hours, 7 days a week that provides local referrals for a wide range of needs, including housing, food assistance, health care, financial support, and more.

Website: [211.org](https://211.org)

Phone Number: 211

Other Resources Available:



### ADDITIONAL TIPS FOR FINDING TRANSPORTATION ASSISTANCE:

- **Local transit companies or organizations:** Start by contacting your local and regional transit organizations. Ask if they have any mobility management programs.
- **Contact your state:** Local aging or disability organizations may be able to provide free or discounted transportation if you meet certain criteria.
- **Check your insurance benefits:** If you have Medicaid, your benefits may include assistance with transportation to and from medical appointments. Call your caseworker or the office in charge of Medicaid in your area to see if help is available.
- **Check with rideshare services:** Ride share services often have options for those that need transportation assistance.

## HEALTHCARE AND WELL-BEING

### Dental

#### Dental Lifeline Network (DLN)

DLN provides access to dental care and education for people who cannot afford it, and who have a permanent disability, or who are elderly (age 65 or older), or who are medically fragile.

**Website:** <https://dentallifeline.org/>

**Phone Number:** 303-534-5360

#### Dentistry From The Heart (DFTH)

DFTH, based in New Port Richey, Florida, is a worldwide nonprofit organization dedicated to providing free dental care to those in need. Every year, thousands of individual dentists, hygienists, volunteers, and hundreds of practices across the world donate their time and resources to host their own DFTH events. In support of our dental organization's providers, DFTH acts to ensure that those in need are advised of the services available through regional press releases and customized YouTube™ videos that promote the practices involved.

**Website:** [Dentistryfromtheheart.org/](http://Dentistryfromtheheart.org/)

**Phone Number:** 727-849-2002



**Medical Care** (medical care, co-pay assistance, medications, diagnostic lab tests, dental, durable medical equipment)

*Medical Care including co-pay assistance and medications:*

#### The Assistance Fund (TAF)

TAF is an independent charitable patient assistance foundation that helps patients and families facing high medical out-of-pocket costs by providing financial assistance for their copayments, coinsurance, deductibles, and other health-related expenses. The Assistance Fund currently manages more than 70 disease programs—each of which covers the FDA-approved medications that treat a specific disease.

**Website:** [TAFcares.org/](http://TAFcares.org/)

**Phone Number:** 855-845-3663

#### Friends of Man

Friends of Man gives help to people who find themselves in a situation where they have nowhere else to turn. The kind of help given by Friends of Man depends on the need. Because Friends of Man is an all-volunteer organization, the application must be filled out by an agency on behalf of the applicant, such as social workers, patient advocate, counselor, or medical professional.

**Website:** [Friendsofman.org](http://Friendsofman.org)

**Phone Number:** 303-798-2342

#### Good Days

Good Days provides financial support by covering prohibitively costly co-pays for those with life-altering conditions, allowing them to receive treatment without destroying their finances. They even offer, in some cases, additional financial assistance for health insurance premiums and treatment-related travel expenses.

**Website:** [Mygooddays.org/](http://Mygooddays.org/)

**Phone Number:** 877-968-7233



### HealthWell Foundation

The HealthWell Foundation is a nonprofit dedicated to improving access to care for America's underinsured. When health insurance is not enough, HealthWell fills the gap by assisting with copays, premiums, deductibles, and out-of-pocket expenses. The foundation provides financial assistance to help with prescription copays, health insurance premiums, deductibles and coinsurance, pediatric treatment costs, and travel costs.

**Website:** [Healthwellfoundation.org/](https://healthwellfoundation.org/)

**Phone Number:** 800-675-8416

### HRSA Health Centers

The Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services, is the main federal agency for improving access to health care services for people who are uninsured, isolated, or medically vulnerable. This tool allows you to search for nearby HRSA facilities up to a 250-mile radius.

**Website:** [Findahealthcenter.hrsa.gov/](https://findahealthcenter.hrsa.gov/)

### National Association of Free and Charitable Clinics (NAFCs)

The mission of the NAFCs is to ensure that the medically underserved have access to affordable, quality health care.

**Website:** [NAFCclinics.org/get-care/](https://nafcclinics.org/get-care/)

**Phone Number:** 703-647-7427

### NeedyMeds

NeedyMeds is a national nonprofit information resource dedicated to helping people locate assistance programs to help them afford their medications and other healthcare costs.

**Website:** [Needymeds.org/](https://needymeds.org/)

**Phone Number:** 800-503-6897

### Patient Advocate Foundation (PAF)

The PAF Co-Pay Relief Program, one of the self-contained divisions of PAF, provides direct financial assistance to insured patients who meet certain qualifications to help them pay for the prescriptions and/or treatments they need. This assistance helps patients afford the out-of-pocket costs for these items that their insurance companies do not cover.

**Website:** [Patientadvocate.org/connect-with-services/copay-relief/](https://patientadvocate.org/connect-with-services/copay-relief/)

**Phone Number:** 800-532-5274 (Case management services and MedCareLines)

**866-512-3861** (Co-Pay Relief Program)

### United Healthcare Children's Foundation (UHCCF)

The UHCCF offers timely financial support to families so they can focus on what is most important – enhancing the quality of life of their child. UHCCF grants help with medical expenses not covered, or not fully covered, by a family's commercial health insurance.

**Website:** [UHCCF.org/](https://uhccf.org/)

### United Way 211

A free, confidential service available 24 hours, 7 days a week that provides local referrals for a wide range of needs, including housing, food assistance, health care, financial support, and more.

**Website:** [211.org](https://211.org)

**Phone Number:** 211

**Other Resources Available:**



### Medication Only Programs:

#### 340b Clinics and Pharmacies

The 340b Drug Pricing Program is a federal program that allows certain health care providers to purchase outpatient prescription drugs at a discount, which can help reduce the cost of drugs for patients. To Find 340b clinics contact the Health Resources & Services Administration (HRSA)

**Website:** [HRSA.gov/opa](https://hrsa.gov/opa)

**Phone Number:** 877-464-4772

### HEALTHCARE AND WELL-BEING (continued)

#### Acthar Gel (repository corticotropin injection)

Acthar Patient Assistance Program is available to patients who are uninsured or underinsured. Patients must have a valid prescription and be a permanent U.S. resident. The Acthar Gel Commercial Co-pay Program is available to eligible patients who are insured but need help affording the co-pay.

**Website:** [Acthar.com/financial-assistance/](https://acthar.com/financial-assistance/)

**Phone Number:** 877-503-7746

#### Benlysta (belimumab)

The BENLYSTA Co-pay Program helps eligible approved patients with their out-of-pocket costs for BENLYSTA up to \$15,000 for 12 months. Medicare-eligible patients and patients enrolled in government-funded programs are not eligible for the BENLYSTA Co-pay Program. Patients must submit a Service Request Form so their eligibility can be determined.

**Website:** [Benlysta.com/savings-and-support.html](https://benlysta.com/savings-and-support.html)

**Phone Number:** 877-423-6597

#### CellCept® (mycophenolate mofetil)

Genentech Access to Care Foundation (GATCF), provides free medicine to eligible patients who are uninsured, rendered uninsured by payer denial, or underinsured. To qualify, patients must meet specific criteria. Genentech Access Solutions requires only the Statement of Medical Necessity (SMN) and Patient Notice of Request for Transmission of Health Information (PAN) to initiate services. Only the information requested on these forms is required.

If patients have a kidney transplant, commercial insurance, and have been prescribed brand-name CellCept, they may be eligible to pay as little as \$15 per monthly co-pay with the CellCept® Co-pay Card.

**Website:** [Cellcept.com/patient/cost-and-financial-assistance.html](https://cellcept.com/patient/cost-and-financial-assistance.html)

**Phone Number:** 888-754-7651

(Genentech® Access to Care Foundation) (Mon-Fri)

833-235-5237 (Co-pay Card Program)

8:00 am - 8:00 pm ET, Mon-Fri

#### Gazyva® (obinutuzumab)

Genentech, the manufacturer of GAZYVA®, offers several programs to help make its medications more affordable. Depending on your insurance coverage and financial situation, you may qualify for copay assistance or other support services. The Genentech Patient Foundation also provides free Genentech medicines to people who don't have insurance and meet certain eligibility criteria.

**Website:** [Genentech-access.com/patient/brands/gazyva-immunology/how-we-help-you.html](https://genentech-access.com/patient/brands/gazyva-immunology/how-we-help-you.html)

**Phone Number:** 866-681-3261

#### Lupkynis® (voclosporin)

Aurinia Alliance is a personalized support program from Aurinia, the company that makes LUPKYNIS, designed to help you better understand lupus nephritis, assist you in navigating insurance and LUPKYNIS funding options, and support you to help stay on track during your LUPKYNIS treatment journey. Once you enroll, you'll be connected with a dedicated Nurse Case Manager, who will be your direct contact throughout the duration of your LUPKYNIS treatment.

**Website:** [Lupkynis.com/resources](https://lupkynis.com/resources)

**Phone Number:** 833-287-4642

#### Medicine Assistance Tool

Helps connect uninsured and underinsured patients who struggle with affordable access to medicines with prescription assistance programs that offer medicines for free or nearly free.

**Website:** [Medicineassistancetool.org](https://medicineassistancetool.org)

### Myfortic (mycophenolic acid)

Novartis is committed to helping people learn about their treatment – and helping patients access the medications they need. You can learn useful information and about prescription savings offers for ZORTRESS® (everolimus) Tablets, myfortic® (mycophenolic acid) delayed-release tablets, Neoral® (cyclosporine capsules, USP) MODIFIED, and SANDIMMUNE® (cyclosporine capsules, USP).

**Website:** [Saveonmyprescription.com/copay.jsp?usertrack.filter\\_applied=true&Novald=3831503029504747913](https://www.saveonmyprescription.com/copay.jsp?usertrack.filter_applied=true&Novald=3831503029504747913)

**Phone Number:** 877-952-1000

### RxAssist

RxAssist is a nationally recognized, web-based medication assistance resource center. Established in 1999 with funding from The Robert Wood Johnson Foundation, RxAssist gives providers, advocates, consumers, and caregivers comprehensive, up-to-date information in an easy-to-use format.

**Website:** [Rxassist.org/](https://www.Rxassist.org/)

### RxHope

RxHope helps people obtain critical medications that they would normally have trouble affording. RxHope acts as an advocate in making the patient assistance program journey easier and faster by supplying information and help.

**Website:** [Rxhope.com/](https://www.Rxhope.com/)

### Saphnelo® (anifrolumab-fnia)

The AstraZeneca Access 360™ program provides you with personal support to help streamline access and reimbursement for select AstraZeneca medicines. Connect with Patient Access Navigators to get answers to your questions about insurance, affording your SAPHNELO medicine, and out-of-pocket costs.

**Website:** [Saphnelo.com/patient/support/savings-support.html](https://www.Saphnelo.com/patient/support/savings-support.html)

[Myaccess360.com/patient/saphnelo-anifrolumab.html](https://myaccess360.com/patient/saphnelo-anifrolumab.html)

**Phone Number:** 844-275-2360  
(8:00 am to 6:00 pm ET, Mon-Fri)

## ADDITIONAL TIPS FOR FINDING MEDICAL CARE AND MEDICATIONS:

- **Charity Care:** Typically offered by hospitals and healthcare organizations to discount or help cover the costs of visits, treatments, procedures, or services. Contact your local hospital, healthcare provider, or organization providing your care to see what programs they offer and if you qualify.
- **Medicaid and Medicare:** Provide assistance for low-income individuals, seniors and those with disabilities. Eligibility varies, so it's important to check the requirements for each.
- **Discount Pharmacies:** Some large retail stores with pharmacies carry generic versions of medicines — these are cheaper than name brand medicines but work exactly the same way. Ask your doctor if you can switch to a generic version.
- **Discount Card:** Consider using a prescription discount card if you do not have insurance such as NeedyMeds Drug Discount Card or others available online. These cards are designed to provide lower medication costs when you pay cash. There's no cost to use a discount card. You can use them with insurance too, but anything you pay will not count towards your deductible.





#### HEALTHCARE AND WELL-BEING (continued)

##### *Diagnostic Testing (lab work)*

###### **Labcorp**

Labcorp offers payment options for patients and shows a chart that explains how the company bills your insurance.

**Website:** [Labcorp.com/bill-pay/payment-options#](https://labcorp.com/bill-pay/payment-options#)

###### **Quest**

Quest offers a patient assistance program with tailored solutions for uninsured or underinsured patients based on individual circumstances.

**Website:** [questdiagnostics.com/patients/billing-insurance/financial-assistance](https://questdiagnostics.com/patients/billing-insurance/financial-assistance)

##### *Durable Medical Equipment (wheelchairs and other aids)*

###### **American Mobility Outreach**

The foundation accepts donations of new or used power chairs and scooters, refurbishes them, and provides them free of charge to individuals in need.

**Website:** [Americanoutreachfoundation.com/](https://Americanoutreachfoundation.com/)

###### **Direct Relief International**

Since its inception, Direct Relief has provided appropriate and specifically requested medical resources, including wheelchair donations, to community-based institutions and organizations in over 140 countries including the United States.

**Website:** [Directrelief.org/](https://Directrelief.org/)

###### **Hope Haven International**

Refurbishes mobility wheelchairs and manufactures pediatric wheelchairs to distribute to physically challenged people around the world through international sponsors.

**Website:** [Hopehaven.org](https://Hopehaven.org)

###### **The Kids Equipment Network**

Provides physically challenged children and youth with refurbished durable medical and adaptive equipment in circumstances when their families do not have the means to pay for mobility aids.

**Website:** [Tken.org/](https://Tken.org/)



### LifeNets – The Wheelchair Project

LifeNets matches donated wheelchairs with needy recipients who cannot afford or qualify for wheelchairs in the United States. The organization networks with medical missionary organizations and individuals to access and provide donated wheelchairs.

**Website:** [Lifenets.org/ or https://lifenets.org/programs/wheelchairs/](https://lifenets.org/programs/wheelchairs/)

**Phone Number:** 513-201-8850

### Magic Mobility Vans by Special Kids Fund

Magic Mobility provides assistance with adapted vehicles for families of individuals with disabilities by collecting donated wheelchair-accessible vans and funding conversions for needy families nationwide.

**Website:** [Magicmobilityvans.org/](https://magicmobilityvans.org/)

### Mobility International USA (MIUSA)

MIUSA is a nonprofit, cross-disability organization serving those with cognitive, hearing, learning, mental health, physical, systemic, vision, and other disabilities. MIUSA's mission is to empower people with disabilities to achieve their human rights through international exchange and international development.

**Website:** [Miusa.org/](https://miusa.org/)

### Steps of Faith Foundation

A nonprofit public charity providing prosthetic limbs to uninsured amputees.

**Website:** [Stepsofffaithfoundation.org/](https://stepsofffaithfoundation.org/)

### Wheelchair Foundation

The Wheelchair Foundation is a nonprofit organization with the goal of providing a free wheelchair to every child, teen, and adult worldwide who needs one but has no means to acquire one.

**Website:** [Wheelchairfoundation.org/](https://wheelchairfoundation.org/)



## Medical Providers

Finding a new doctor can be a lot of effort, and it can be a complicated process.

There is no one single recognized center of excellence for the treatment and diagnosis of lupus in the United States today.

The general recommendation is to find a physician who is affiliated with a medical school—a university hospital, for example. They are generally regarded as very good places to go for the diagnosis and treatment of lupus.

Here are some helpful resources to find a doctor near you:

### Cardiologists

American Heart Association's tool to find a heart specialist.

**Website:** [Heart.org](https://heart.org)

**Phone Number:** 800-242-8721

### Dermatologists

American Academy of Dermatology's tool to find a skin specialist.

**Website:** [AAD.org](https://aad.org)

**Phone Number:** 888-462-3376

### Gastroenterologist

American College of Gastroenterology Find a GI Doctor

**Website:** [Gi.org/patients/find-a-gastroenterologist/](https://gi.org/patients/find-a-gastroenterologist/)

### Hematologist

American Society of Hematology Find A Hematologist

**Website:** [Hematology.org/education/patients/find-a-hematologist](https://hematology.org/education/patients/find-a-hematologist)

### Neurologist

American Neurological Association  
Member Directory Search

**Website:** [Myana.org/member-directory](https://myana.org/member-directory)

### Perinatologist (Maternal-Fetal Medicine MFM)

Society for Maternal Fetal Medicine Find an MFM Search

**Website:** [SMFM.org/find-an-mfm](https://smfm.org/find-an-mfm)

### Rheumatologists

### HEALTHCARE AND WELL-BEING (continued)

American College of Rheumatology Provider Directory

Website: [My.rheumatology.org/rheumatology-provider-directory](https://my.rheumatology.org/rheumatology-provider-directory)

### Screening and Prevention Resources

#### Kidney Screenings

National Kidney Foundation

Website: [Kidney.org](https://kidney.org)

Phone Number: 800-622-9010

#### LabCorp

Find lab locations for blood tests and urinalysis.

Website: [Labcorp.com](https://labcorp.com)

Phone Number: 800-845-6167

#### Quest Diagnostics

Find lab locations for blood tests and urinalysis.

Website: [Questdiagnostics.com](https://questdiagnostics.com)

Phone Number: 866-697-8378

#### Vaccine Guidelines for Individuals with Rheumatic Diseases

American College of Rheumatology (ACR)

Website: [Rheumatology.org/patient-blog/vaccine-guidelines-for-individuals-with-rheumatic-and-musculoskeletal-diseases](https://rheumatology.org/patient-blog/vaccine-guidelines-for-individuals-with-rheumatic-and-musculoskeletal-diseases)

Phone Number: 404-633-3777



### STILL NEED HELP FINDING A HEALTH CARE PROFESSIONAL?

The Lupus Foundation of America's Health Education

Specialists are available to help you! To talk with a Health Education Specialist today call 1-800-558-0121 or visit [Lupus.org/ask-an-educator](https://lupus.org/ask-an-educator).



## Navigating Health Insurance

### Consumer Assistance Program (CAPs)

Many States have established CAPs in order to better assist consumers experiencing problems with their health insurance or seeking to learn about health coverage options.

Website: [CMS.gov/ccio/resources/consumer-assistance-grants#statelisting](https://cms.gov/ccio/resources/consumer-assistance-grants#statelisting)

### Health Insurance Marketplace

A service that helps people shop for and enroll in health insurance. The federal government operates the Health Insurance Marketplace®, available at HealthCare.gov, for most states. Some states run their own Marketplaces. The Health Insurance Marketplace® (also known as the “Marketplace” or “exchange”) provides health plan shopping and enrollment services through websites, call centers, and in-person help.

Website: [Healthcare.gov](https://healthcare.gov)

Phone Number: 800-318-2596

### Insurance Guidance

### Centers for Medicare & Medicaid Services (CMS)

Website: [CMS.gov](https://cms.gov)

Phone Number: 800-633-4227

### Lupus Foundation of America Health Insurance Guide for People with Lupus

This guide aims to clarify what health insurance is and how selecting the right plan can support effective lupus management. This guide includes information about health insurance basics, lupus-specific considerations for health insurance, how to advocate for yourself and other ways to pay for health care.

Website: [Lupus.org/health-insurance-guide](https://lupus.org/health-insurance-guide)



### MAPRx Coalition

Medicare Part D provides prescription drug coverage for more than 50 million of America's seniors and those living with chronic diseases like lupus. Part D allows timely, affordable access to lifesaving therapies, and the MAPRx Coalition ensures the program continues to serve those who need it.

### Medicare Part D Open Enrollment Guides

**Website:** [Lupus.org/medicaid-maprx](https://lupus.org/medicaid-maprx)

### My Patient Rights

My Patient Rights aids patients who have experienced difficulty affording health care from their health plans. If your health plan has denied any health care services or prescriptions, or if you have experienced any other barriers, My Patient Rights can help resolve these problems.

**Website:** [Mypatientrights.org/](https://mypatientrights.org/)

**Phone Number:** 916-531-3585

### My Smile Insured

Advocates in the dental industry who help patients access their medical insurance benefits for their dental care.

**Website:** [Mysmileinsured.com/](https://mysmileinsured.com/)

### National Association of Insurance Commissioners (NAIC)

NAIC provides contact information for insurance departments, information for local insurance agents, and information about filing a complaint.

**Website:** [Content.naic.org/](https://content.naic.org/)

### State Health Insurance Assistance Programs (SHIPs)

The State Health Insurance Assistance Programs (SHIPs) provide local, in-depth, and objective insurance counseling and assistance to Medicare-eligible individuals, their families, and caregivers.

**Website:** [Shiphelp.org/](https://shiphelp.org/)

### Triage Health

Legal & Financial Navigation Program  
Triage Health provides individuals diagnosed with a serious or chronic medical condition, their caregivers, and health care professionals with free one-on-one help in the areas of health insurance, disability insurance, employment, finances, medical decision-making, estate planning, and more. They are trained to help you find your way – or navigate – through the legal, financial, and practical barriers that you face as you access care.

**Website:** [Triagehealth.org/legal-and-financial-navigation-program/](https://triagehealth.org/legal-and-financial-navigation-program/)

**Other Resources Available:**



## GETTING THE SUPPORT YOU NEED



### Child Care

#### Child Care Financial Assistance (also called vouchers, certificates, or subsidies)

States and territories receive funding from the federal government to provide child care financial assistance to help low-income families pay for child care so they can work or attend school. Eligibility requirements are different in each state.

**Website:** [Childcare.gov/state-resources](https://childcare.gov/state-resources) and [select your state or territory to find resources](#)

#### Head Start, Early Head Start and State-Funded Pre-Kindergarten

Head Start and Early Head Start programs help prepare children from birth to age 5 for school and provide services to support children's early learning and development, mental well-being, and physical health. State-funded prekindergarten programs serve children between 3 and 5 years of age and focus on helping children get ready for kindergarten. Some states offer these programs to eligible families at low or no cost.

**Website:** [Childcare.gov/state-resources](https://childcare.gov/state-resources) and [select your state or territory to find resources](#)



### Disability

#### Career One Stop

CareerOneStop is the flagship career, training, and job search website for the U.S. Department of Labor. Information is available for workers with disabilities.

**Website:** [Careeronestop.org/ResourcesFor/WorkersWithDisabilities/workers-with-disabilities.aspx](https://careeronestop.org/ResourcesFor/WorkersWithDisabilities/workers-with-disabilities.aspx)

#### Centers for Independent Living (CILs)

Designed and operated by individuals with disabilities, CILs provide independent living services for people with disabilities.

**Website:** [ACL.gov/programs/centers-independent-living/list-cils-and-spils](https://acl.gov/programs/centers-independent-living/list-cils-and-spils) to find centers by State

**Other Resources Available:**



#### Disability Discrimination - File a Complaint

If you believe that you or someone else was discriminated against based on a disability, you can file an Americans with Disabilities Act (ADA) complaint.

**Website:** [ADA.gov/file-a-complaint/](https://ada.gov/file-a-complaint/) to learn more about how to file your complaint

#### Job Accommodation Network (JAN)

JAN is the leading source of free, expert, and confidential guidance on job accommodations and disability employment issues.

**Website:** [Askjan.org/](https://askjan.org/)

**Phone Number:** 800-526-7234

**Other Resources Available:**



#### National Disability Institute (NDI)

The NDI offers resources and assistance to help individuals with disabilities and chronic health conditions manage financial challenges during difficult times.

**Website:** [Nationaldisabilityinstitute.org/financial-resilience-center/](https://nationaldisabilityinstitute.org/financial-resilience-center/)

#### National Disability Rights Network (NDRN)

The NDRN provides protection and advocacy for individuals with disabilities. Their members provide legal representation and other advocacy services to all people with disabilities.

**Website:** [NDRN.org/](https://ndrn.org/)





### **National Organization of Social Security Claimants' Representatives (NOSSCR)**

The mission of the National Organization of Social Security Claimants' Representatives (NOSSCR) is to advocate for improvements in Social Security disability programs and to ensure that individuals with disabilities applying for Social Security Disability and SSI benefits have access to highly qualified representation and receive fair decisions.

**Website:** [Nossr.org/](https://nossr.org/)

**Phone Number:** 202-849-6466

### **Social Security Disability Insurance (SSDI)**

Social Security Disability Insurance (SSDI) or "Disability" provides monthly payments to people who have a disability that stops or limits their ability to work.

**Website:** [SSA.gov/disability](https://ssa.gov/disability) to learn more

**Disability Starter Kit:** [SSA.gov/disability/disability\\_starter\\_kits.htm](https://ssa.gov/disability/disability_starter_kits.htm)

### **Triage Health**

Legal & Financial Navigation Program

Triage Health provides individuals diagnosed with a serious or chronic medical condition, their caregivers, and health care professionals with free one-on-one help in the areas of health insurance, disability insurance, employment, finances, medical decision-making, estate planning, and more. They are trained to help you find your way – or navigate – through the legal, financial, and practical barriers that you face as you access care.

**Website:** [Triagehealth.org/legal-and-financial-navigation-program/](https://triagehealth.org/legal-and-financial-navigation-program/)

**Other Resources Available:**





## GETTING THE SUPPORT YOU NEED (continued)



## Education/School

### Assistance at School (504 plan and IEPs)

If you or your child experiences any learning problems at school that are caused by or related to lupus, extra assistance or adjustments may be needed at school. You or your child may be legally entitled to such changes if they are deemed to have a disability. The specific assistance that a person who has lupus may receive depends on their individual needs and may include a 504 plan and/or Individualized Education Plan (IEP).

**Website:** [ED.gov/laws-and-policy/civil-rights-laws/disability-discrimination/frequently-asked-questions-section-504-free-appropriate-public-education-fape](https://www.ed.gov/laws-and-policy/civil-rights-laws/disability-discrimination/frequently-asked-questions-section-504-free-appropriate-public-education-fape)

### Center for Parent Information & Resources (CPIR)

These centers provide parents with critical information about the relevant processes, their child's rights, and the parent's rights under the Individuals with Disabilities Education Act (IDEA) and section 504. They can answer questions and give practical advice on issues specific to your area.

**Website:** [Parentcenterhub.org/](https://parentcenterhub.org/)

### Council of Parent Attorneys and Advocates (COPAA)

The council protects and enforces the legal and civil rights of students with disabilities and their families. They enable parents to work more effectively with school personnel to plan and obtain effective educational programs for their children with disabilities.

**Website:** [COPAA.org/default.aspx](https://COPAA.org/default.aspx)

### Lupus Foundation of America Lupus at School: A Guide for Parents and Kids

Communicating with school should be easy. Download this template to customize a letter for school officials informing them of your child's lupus, and asking for a meeting to discuss adjustments, assistance, and any other issues.

**Website:** [Lupus.org/school-guide](https://Lupus.org/school-guide)

### Lupus Foundation of America School Survival Guide for Teens with Lupus

Lupus can be a lot to deal with on top of the demands of middle and high school. Download this guide to help keep your school days fun, productive and healthy!

**Website:** [Lupus.org/school-survival-guide](https://Lupus.org/school-survival-guide)

### National Association of State Directors of Special Education, Inc. (NASDSE)

The association provides leadership to ensure the provision of a quality education to every child. It focuses on improving educational services and outcomes for children and youth with disabilities throughout the United States.

**Website:** [NASDSE.org/](https://NASDSE.org/)

### *Paying for School*

#### FinAid! The SmartStudent Guide to Financial Aid

Financial aid helps students and their families pay for college. It can cover a range of educational expenses, like tuition and fees, room and board, books and supplies, and transportation.

**Website:** [Finaid.org/](https://Finaid.org/)

#### FinAid! The SmartStudent Guide to Financial Aid – Financial Aid for Students with Disabilities

Just as there are scholarships and financial aid opportunities exclusively for women and minorities, there are similar offerings for students with disabilities.

**Website:** [Finaid.org/otheraid/disabled.phtml](https://Finaid.org/otheraid/disabled.phtml)

### Patient Advocate Foundation's Scholarship for Survivors

Provides support to individuals under the age of 25, who have been diagnosed with or treated for cancer and/or a chronic/life threatening disease within the past 5 years.

**Website:** [Patientadvocate.org/connect-with-services/apply-for-a-scholarship/](https://patientadvocate.org/connect-with-services/apply-for-a-scholarship/)

### Scholarships.com

Scholarships.com is a free college scholarship search platform that matches you to college scholarships you qualify for.

**Website:** [Scholarships.com/](https://scholarships.com/)

### U.S. Department of Education – Grants and Scholarships

The Department of Education administers grant funding programs that fulfill the Department's mission to promote student achievement and preparation for global competitiveness, to foster educational excellence, and to ensure equal access.

**Website:** [ED.gov/grants-and-programs/apply-grant/available-grants](https://ed.gov/grants-and-programs/apply-grant/available-grants)



## Employment

### Career One Stop

CareerOneStop is the flagship career, training, and job search website for the U.S. Department of Labor.

**Website:** [Careeronestop.org/](https://careeronestop.org/)

**Phone Number:** 877-872-5627 to reach the employment and training helpline.

### Job Accommodation Network (JAN)

JAN is the leading source of free, expert, and confidential guidance on job accommodations and disability employment issues.

**Website:** [Askjan.org/](https://askjan.org/)

**Phone Number:** 800-526-7234

**Other Resources Available:**



### ADDITIONAL TIPS FOR FINDING CHILD CARE ASSISTANCE:

- **Local assistance and scholarships:** Local nonprofit organizations and individual child care providers may offer fee assistance or scholarships. Ask the providers that you are considering if they offer any child care assistance or scholarships.
- **Sibling discount:** Some child care programs offer a discount to families that enroll siblings. They may take a percentage or a specific dollar amount off of a child's weekly or monthly fee. They may also waive the registration fee or other fees. If you need care for more than one child, ask providers whether they offer sibling discounts.
- **Military discount:** Some civilian child care providers (not associated with military child care) offer discounts for military service members. Ask potential providers if they offer a military discount.



#### GETTING THE SUPPORT YOU NEED (continued)

### Triage Health

#### Legal & Financial Navigation Program

Triage Health provides individuals diagnosed with a serious or chronic medical condition, their caregivers, and health care professionals with free one-on-one help in the areas of health insurance, disability insurance, employment, finances, medical decision-making, estate planning, and more. They are trained to help you find your way – or navigate – through the legal, financial, and practical barriers that you face as you access care.

**Website:** [Triagehealth.org/legal-and-financial-navigation-program/](https://www.triagehealth.org/legal-and-financial-navigation-program/)

#### Other Resources Available:



### Unemployment Insurance

Unemployment insurance is a joint state-federal program that provides cash benefits to eligible workers. Each state administers a separate unemployment insurance program, but all states follow the same guidelines established by federal law.

**Website:** [DOL.gov/general/topic/unemployment-insurance](https://www.dol.gov/general/topic/unemployment-insurance) to learn more and find your own state's program.



### General Financial Assistance

#### Findhelp

Find free or reduced-cost resources like food, housing, financial assistance, health care, and more.

**Website:** [Findhelp.org/](https://www.findhelp.org/)

#### Other Resources Available:



#### Modest Needs

Offers grants designed to promote the self-sufficiency of individuals and families who, because they are working and live just above the poverty level, are ineligible for most types of conventional social assistance but who are living one or two lost paychecks away from the kind of financial catastrophe that eventually leads to homelessness.

**Website:** [Modestneeds.org/](https://www.modestneeds.org/)



### United Way 211

A free, confidential service available 24 hours, 7 days a week that provides local referrals for a wide range of needs, including housing, food assistance, health care, financial support, and more.

**Website:** [211.org](https://www.211.org)

**Phone Number:** 211

**Other Resources Available:**



### Holiday Assistance for Presents

#### St. Vincent de Paul

There are local St. Vincent de Paul societies, it is recommended to look at the National Society listed as well as search for a local society to the constituent. Each year hundreds of families in need turn to St. Vincent de Paul to make Christmas special through the Adopt a Family program.

**Website:** [SVDPusa.org/](https://www.SVDPusa.org/)

#### The Salvation Army

The Salvation Army Angel Tree program helps provide Christmas gifts for the hundreds of thousands of children around the country each year.

**Website:** [Saangeltree.org/](https://www.Saangeltree.org/)

**Other Resources Available:**



#### Toys for Tots

The primary goal of Marine Toys for Tots is, through the gift of a new toy, help bring the joy of Christmas and send a message of hope to America's economically disadvantaged children.

**Website:** [Toysfortots.org/request-a-toy/](https://www.Toysfortots.org/request-a-toy/)



### Mental Health

#### Crisis Text Line

The Crisis Text Line is a text-based mental health support and crisis intervention with trained volunteers to support people in need.

**Website:** [Crisistextline.org/](https://www.Crisistextline.org/)

**Text:** HOME to 741741

#### The Hopeline

The HopeLine is a dedicated crisis line for students and young adults through online communication.

**Website:** [Thehopeline.com/](https://www.Thehopeline.com/)

#### Mental Health America (MHA)

MHA is a community-based nonprofit that addresses the needs of people with mental illness and promotes the overall mental health of all. They also offer several affiliate peer programs in various states to integrate both health and wellness into recovery.

**Website:** [Mhanational.org](https://www.Mhanational.org)

#### National Alliance on Mental Illness (NAMI)

NAMI, the largest mental health grassroots organization, provides education, advocacy, awareness, and support for those with mental illnesses to live better lives.

**Website:** [NAMI.org](https://www.NAMI.org)

**Phone Number:** 800-950-6264

**Text:** NAMI to 62640

#### National Domestic Violence Hotline

The National Domestic Violence Hotline provides essential tools and support to help survivors of domestic violence so they can live their lives free of abuse.

**Website:** [Thehotline.org](https://www.Thehotline.org)

**Phone Number:** 800-799-7233

**Text:** START to 88788

### GETTING THE SUPPORT YOU NEED (continued)

#### National Suicide and Crisis Lifeline

The National Suicide Prevention Lifeline offers free and confidential support for people in distress, along with prevention and crisis resources. The line is open 24 hours, 7 days a week.

**Website:** [988lifeline.org/](https://988lifeline.org/)

**Phone Number:** 9-8-8 or 800-273-7233

#### Online Therapy Directory

The Online Therapy Directory helps people who need mental health services find teletherapy services online.

**Website:** [Onlinetherapy.com/](https://Onlinetherapy.com/)

**Phone Number:** 800-258-9936

#### Psychology Today

An online destination for mental health and behavioral science that allows free access to professionals. Users can find therapists, treatment centers, support groups, and more to access care. People can also find more information on mental health diagnosis, personality, personal growth, relationships and family life.

**Website:** [Psychologytoday.com/us](https://Psychologytoday.com/us)

#### Substance Abuse and Mental Health Services Administration (SAMHSA)

This is an agency within the Department of Health and Human Services (HHS) designed to promote mental health, prevent substance misuse, and provide treatments and support to foster recovery while ensuring equitable access and better outcomes.

**Website:** [SAMHSA.gov](https://SAMHSA.gov)

**Phone Number:** 800-662-4357

#### The Trevor Project

A website dedicated to helping young people who identify as gay, lesbian, transgender, queer, or non-binary. A counselor is available 24 hours, 7 days a week.

**Website:** [Thetrevorproject.org/get-help/](https://Thetrevorproject.org/get-help/)

**Phone Number:** 866-488-7386

#### United Way 211

A free, confidential service available 24 hours, 7 days a week that provides local referrals for a wide range of needs, including housing, food assistance, health care, financial support, and more.

**Website:** [211.org](https://211.org)

**Phone Number:** 211

**Other Resources Available:**



#### Veterans Crisis Line

A hotline dedicated to veterans and their loved ones who may be experiencing a crisis. Access is free and available 24 hours a day, 7 days a week all year.

**Website:** [Veteranscrisisline.net/](https://Veteranscrisisline.net/)

**Phone Number:** 9-8-8, then press 1

**Text:** 838255





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